

EHU Consortium Report – November 2003

Introduction

In 2002, Congress funded the Centers for Disease Control (CDC) with \$17.5 million to begin developing a nationwide environmental public health tracking system. Maine was successful in receiving a 3-year planning grant to work with the CDC in developing a National environmental public health tracking network. The goal is to develop a tracking system that integrates data about environmental hazards and exposure with data about diseases that are possibly linked to the environment. This system will allow federal, state, and local agencies to advance research on possible linkages between environmental hazards and disease.

Maine has a rather extensive and unique set of environmental databases that are available for assessment and possible inclusion in a larger national surveillance system. However, there is currently a significant gap in the state's ability to track diseases triggered or exacerbated by environmental causes. A collaborative of state-wide stakeholders was brought together to form a Consortium with the intent of advising and providing recommendations to the Maine Bureau of Health on: 1) needs and concerns of data users and stakeholders related to tracking health effects, exposures and hazards; and 2) priority health effects, environmental exposure, and hazard tracking systems to be enhanced or developed as part of a tracking system for Maine.

Process

To achieve project objectives three planning consortium meetings were scheduled. The first meeting, a facilitated session, focused on identifying the needs and concerns of data users and stakeholders. Consortium members were provided with resource documents in preparation for the session. A facilitator, with experience in environmental issues, led the process. Several questions were developed and shared with the consortium in advance of the meeting. Member responses and themes are documented as follows.

Summary of Findings

Attributes (Characteristics) of a Maine Environmental Public Health Tracking System (EPHT)

In response to the question of what the attributes of an EPHT system would be, participants generated the following.

- A high quality system that incorporates a strong investment in validation of data and quality of information being generated, and a description of the data source prior to linkage with other databases.
- A system with the ability to integrate various databases (health, hazard, exposure) that can be analyzed and results utilized in informing public health decisions

- A system design cognizant of types of data being generated and compatibility of various sources
- A system that has the capacity to identify emerging issues, identify patterns that address associations between environmental hazard and health data, and seeks opportunities to discern validity between environment and health
- A system that considers local level infrastructure and ability to participate in data generation
- A system that includes a peer review group whose responsibility is to evaluate data sources resulting in improved data collection
- A system that has wide-spread access with formal policies and procedures around levels of data access and release

When asked about EPHT system concerns in Maine, the following statements were made.

- Aggregate data being de-identified is a major concern with public access and data sharing, degree of accuracy, and usability of data generated
- Concentrated focus on concerns could stymie progress thus losing sight of the future benefit
- Ability to collect local level data if communities do not have the capacity to generate
- Entity responsible for integration and interpretation – state or data generators and impact of HIPAA/FERPA in this process. Existing state and federal databases need to be inventoried and evaluated to prevent duplication and ensure what emerges adds value, refrain from duplicating existing data
- Past history (focusing on specific perspective) may hamper thinking outside the box, this effort involves sharing databases which may involve new data tools

Data Access and Sharing Issues

The following documents the groups perceptions of what additional legislation or regulatory authority may be required to obtain or share data.

- Confidentiality and privacy are major issues in Maine and HIPAA has further complicated. Title 22 Chapter 271 Section 1692 (b) [Investigations] should be examined to determine if there is a need for the restrictions. Review Immunity statute for health care providers to determine if it shields data generators from providing data to EPHT system
- MaineCare data is restricted by CMS to aggregate reporting and can only be used for advancing the Medicaid population
- A potential work product of this effort could be recommended statutory/regulatory changes on such issues as researchers willingness to share data, agency interpretation of rules on data sharing, private funding source data sharing, access – who has, level of and intended use

On the question of ownership and access to existing or new data sources responses included

- The primary issue around access is privacy and the potential of de-identifying data or individuals having access to data that would then be misinterpreted
- Due to sensitive nature of data perhaps have legislative oversight of major substantive rules on BOH use of data

Prioritization of Environmental Public Health Indicators

When asked what criteria to consider when determining how to prioritize, members shared the following.

- Highest priority should be given to those indicators where linkage is clearer i.e., ozone and ED visits; where impact on community(s) more heavily burdened by an exposure and disparity of impact on subpopulations; attributes that increase the likelihood of an environmental role, while at the same time keeping legal impediments in mind. Indicators lacking clear access should receive a lower rating until access issues are worked out
- Utilize existing data initially keeping in mind cost to obtain. Since this is a staged development system, we may rank some indicators high even if costly, the challenge is to determine a mechanism to accomplish. If not currently monitoring, investigate potential of emerging technology that would present new opportunities
- Determine a methodology to take action on indicators with similar ratings
- Greater emphasis (higher priority) placed on more common events

Discussion

A key element in the successful planning and implementation of an environmental public health tracking system for Maine is to further establish and maintain solid relationships with our stakeholders. This process provided a forum whereby a very diverse group of individuals were encouraged to have an open dialogue about their hopes and concerns of an EPHT system for Maine. While we do not, at this time, have a clear picture of the end product we have the beginnings of a strong foundation. Future sessions will build upon input generated during this dialogue.